



**NJ Department of Health  
Governor's Council for Medical Research and Treatment of Autism  
Council Meeting Minutes (ratified)  
September 12, 2016**

**Council Members Present**

**Michael Aquino, MD, F.A.C.G.**, Senate President Appointee; Partner, Shore Gastroenterology Associates, Cofounder, VP of Operations, Pathology Solutions

**Elizabeth K. Bell, BS**, Public Member - Individual or Family Member with Autism Representative; Volunteer and Independent Contractor with Autism Speaks

**Cheryl F. Dreyfus, Ph.D.**, Academic Institution Representative; Professor and Chair, Department of Neuroscience and Cell Biology, Rutgers University, Robert Wood Johnson Medical School

**\*Caroline Eggerding, MD**, Healthcare Organization Representative; Division Head, Department of Pediatric Neurology and Development, Cooper Children's Regional Hospital

**Wilma Judith Friedman, Ph.D.**, Academic Institution Representative; Professor, Department of Biological Sciences, Rutgers University

**Thomas V. Macchiaverna, MA**, Public Member Representative; Special Education Teacher

**Samuel Sheng-Hung Wang, Ph.D.**, Academic Institution Representative; Professor, Department of Molecular Biology and Princeton Neuroscience Institute, Princeton University

**Gary Weitzen, BA**, Autism Organization Representative; Executive Director of POAC (Parents of Autistic Children)

\*Denotes Council Chairperson

**Absent**

**Susan P. Evans, Ed.D.**, Commissioner of Health Appointee; Education Program Specialist for Early Intervention Program, NJ Department of Health

**B. Madeleine Goldfarb, MA**, Autism Organization Representative; Founder/Director of the Noah's Ark Institute

**Ketan Kansagra, MD, FAAP**, Academic Institution Representative; Division of Neonatal Medicine, Children's Hospital of New Jersey at Newark Beth Israel Medical Center

**Dana E. Spett, MSW**, Autism Organization Representative; Founder/Executive Director, Pony Power Therapies

**NJ Department of Health (DOH) Attendees**

Martin T. Zanna MD, MPH, Acting Executive Director  
Governor's Council for Medical Research and Treatment of Autism

Linda N. Bocclair, M.Ed., MBA, Executive Assistant  
Governor's Council for Medical Research and Treatment of Autism

Mary Ray, Contract Administrator 2  
Governor's Council for Medical Research and Treatment of Autism  
Commission on Brain Injury Research and Commission on Spinal Cord Research

Daphne Robinson, Ph.D., Consultant  
Scientific Planning Consulting

**Public Attendees**

Gerard Costa, Ph.D., Center for Autism and Early Childhood Mental Health at Montclair State University and Principal Investigator, NJ ACE Coordinating Center

Cecelia Feeley, Ph.D., Rutgers University

Karen Hood-Kasim MPH, Project Coordinator, NJ ACE Coordinating Center

Charles Matteis, Ph.D., Strategic Planning Consultant, NJ ACE Coordinating Center

Harumi Jyonouchi, M.D., Saint Peter's University Hospital

**I. Welcome** - Council Chairperson, Dr. Caroline Eggerding called the meeting to order at 6:05 PM and welcomed everyone.

**II. Public Meetings Act Announcement**- Dr. Eggerding read the Public Meetings Act, followed by roll call.

**III. Approval of the May 26, 2016 Council Meeting Minutes**-Dr. Eggerding called for a motion to approve the minutes. MOTION by Dr. Friedman to approve the minutes was seconded by Mr. Macchiaverna.

**MOTION to approve the minutes was passed with six in favor and two abstentions.**

**IV. Approval of 2017 Council Meeting Calendar-** Dr. Eggerding called for a motion to approve the calendar. MOTION by Dr. Dreyfus to approve the calendar was seconded by Dr. Friedman.

**MOTION to approve the 2017 Council Meeting Calendar was approved with all members in favor.**

**V. Continuation funding for Grant # CAUT12ACC012: The Coordinating Center at Montclair State University (CC-MSU)**

Dr. Eggerding called for a motion to approve Grant # CAUT12ACC012 for year five continuation funding.

MOTION by Mr. Weitzen to approve CAUT12ACC012 for year five continuation funding was seconded by Dr. Dreyfus.

Dr. Zanna highlighted the following accomplishments of the Coordinating Center, referring to the summary of the Center's 2015-2016 Annual Report included in Council's meeting packets:

- During this project year, the NJ ACE CC-MSU convened 13 meetings, trainings and other sessions related to the goals and objectives of NJ ACE, with outcomes listed in the Annual Report.
- The NJ ACE CC-MSU provided feedback and support to all NJ ACE Program and Pilot sites at least five times each quarter, for a total of more than 180 points of contacts.
- Site Visits/Orientation - The NJ ACE CC-MSU representatives made site visits to all NJ ACE researchers with the exception of two grantees. Site visits are useful in relationship building with grantees and in garnering a deeper understanding of the research.
- Recruitment-The NJ ACE CC-MSU team supported NJ ACE PIs with recruitment efforts throughout the fiscal year using a variety of strategies listed in the Annual Report.
- By participating or attending conferences and events, the CC-MSU disseminated knowledge gained through the research efforts of the NJ ACE to families of children with ASD and providers of care by hosting or participating in various events.

Dr. Zanna recommended the grant be presented to Council for continuation funding.

**MOTION to approve continuation funding for year five for Grant #CAUT12ACC012 was approved with all members in favor.**

## **VI. Approval of Council's Vision and Mission Statements**

The Council discussed the following Vision and Mission statements developed at their June 6, 2016 Strategic Planning meeting:

- Vision: To enhance the lives of individuals with ASD across their lifespans
- Mission: To advance and disseminate the understanding, treatment, and management of ASD by means of a coordinated program of biomedical research, clinical innovation, and professional training in New Jersey

Dr. Eggerding called for a motion to approve the Vision and Mission Statements.

MOTION by Dr. Friedman to approve the Council's Vision and Mission Statements was seconded by Ms. Bell.

**MOTION to approve the Council's Vision and Mission statements was approved with all members in favor.** The Vision and Mission statements will be included in publications such as annual reports and RFAs and posted on the Council's webpage.

The Council then considered if the NJACE Mission\* statement should be revised or removed from documents and the webpage. If it is to remain and be revised "prevention" can no longer be included in the statement, per a decision in March 2015 by the Department of Health's (DOH) Legislative Office citing it is misleading to state in a public document that autism is preventable.

A lengthy discussion ensued regarding the use of "prevention" in the statement with a majority of members presenting facts to support the inclusion of "prevention" in the NJACE Mission statement. It should be noted, in addition to the facts discussed, "prevention" is included in the Council's Establishing Legislation, P.L. 2007, c.168 "... basic and clinical research into the cause, diagnosis, early detection, prevention, control and treatment of autism, including research in the fields..." P.L. 2007, c. 168 is a public document.

**Dr. Eggerding presented options to address the question of revising or removing the statement from documents. Members decided to table the discussion and invite the representative from the Department's Legislative Office (Victoria Brogan) to the December 5, 2016 Council meeting to discuss the Mission statement. Jonathan Sabin, Director of the Office on Autism will also be invited to the meeting.**

\*The mission of the NJ ACE is to research, apply and advance best practices in the understanding, prevention, evaluation and treatment of autism spectrum disorders (ASD), enhancing the lives of individuals across their lifespans.

## **VII. Presentation by Dr. Cecelia Feeley (final grant report)**

Dr. Feeley presented her research project entitled “An Assessment of the Transportation and Mobility Needs and Barriers of Adults on the Autism Spectrum Disorder in New Jersey”. Through the analysis of travel patterns, travel needs, and lost opportunities due to disability, the study provided recommendation for procedures and policies that can have positive impacts on the quality of life of the target population. The presentation was followed by a Q&A session. Dr. Eggerding, on behalf of the Council, thanked Dr. Feeley for her most informative presentation.

## **VIII. Presentation by Dr. Harumi Jyonouchi (Final grant report)**

Dr. Jyonouchi presented her research project entitled “Autism Spectrum Disorder-Inflammatory Subtype: Molecular Characterization”. The aim of the study was to evaluate the association between innate immune abnormalities and behavioral symptoms by studying children whose clinical features are indicative of immune abnormalities; they have fluctuating behavioral changes following immune insults (typical microbial infection), adverse reactions to multiple medications and foods, and persistent gastrointestinal (GI) symptoms. The results of the study indicate that IL-1 $\beta$ /IL-10 (inflammatory cytokines) ratios produced by PB Mo (peripheral blood monocytes), as well as expression of certain miRNA (microRNA), can serve as candidate biomarkers for ASD children with dysregulated innate immune responses. In addition, these children may be at risk of developing immune mediated inflammation. The presentation was followed by a Q&A session. Dr. Eggerding, on behalf of the Council, thanked Dr. Jyonouchi for her most informative presentation.

## **IX. NJ ACE Coordinating Center Update – Gerard Costa, Ph.D.**

Dr. Costa thanked the Council for approving continuation funding for the Coordinating Center. He then presented a summary of the Coordinating Center’s activities and services focusing on three major activities: Communications and Outreach, planning for the 2017 Autism Summit and the NJACE CC-MSU strategic planning. Dr. Costa referred to the previous report by Dr. Zanna and provided details for each of the activities including numbers of encounters and outcomes. He referred to the Autism Summit 2017 information included in the Council’s packets, describing in detail the planning process and the agenda.

Discussion: Dr. Costa was asked if he referred to the national research priorities for autism as defined by NIH’s Interagency Autism Coordinating Committee (IACC) in determining content areas for the presentations at the Summit. He responded saying while the planning committee recognizes and respects the work of the IACC, they were asked to “think outside the box” and explore areas of research that may go beyond the IACC objectives.

## **X. Acting Executive Director Report- Martin T. Zanna, MD, MPH**

Dr. Zanna thanked Dr. Costa for his presentation about the work of the Coordinating Center.

**Ethics Requirements-** For those members who have not fulfilled their ethics requirements, please do so within the next week. We are required by the State Ethics Commission to document compliance.

**SFY'17 RFA-** Thank you again to the Chairs and members of the SFY'17 RFA Committees for their work. The RFA was posted on July 26, 2016 on Council's webpage and on the on-line DOH Grants Directory in addition to mailings to over 350 potential applicants. After several months of developing and testing the new basic science application in SAGE and updating the clinical/translational and medical homes applications all three applications were posted on SAGE on August 16, 2016. Letters of Intent are due October 4, 2016, applications are due by November 3, 2016 with Council voting for funding on March 6, 2017.

**Report on NJ ACE Grantees-** Now that we are hearing reports from grants that have closed I want to give you an overview of the status of the 36 grants funded by the Council since 2012. Thanks to Drs. Feely and Jyonouchi for reporting on their grants, the first 2 grants to close. 3 additional grants, those of Drs. Stein, Kerwin and Mintz are in the process of closing. Of the remaining 31 grants, 23 will either have closed or be in no cost extensions by June of 2017. That leaves a total of 8 grants in SFY'18 in addition to up to 7 new grants to be funded in 2017.

**Council -** Rachel Hammond, DOH Ethics Officer, is reviewing with the State Ethics Commission our request to permit Council members who are employees of Rutgers to vote on grant applications and grants from Rutgers as long as the grant applications/grants are not from or connected to the Council member's home campus. We anticipate a response before the next Rutgers grant (Dr. Millonig is the PI) is up for continuation funding at the December 5, 2016 Council meeting.

**Medical Homes Grants-**As Dr. Costa mentioned in his report we are preparing to transfer oversight of the autism medical homes grants to the Coordinating Center within the next month. By then we anticipate all three grantees will have completed the deliverables required to set up their systems including project charters, HIT assessments, workflow maps and action plans. Now they will continue implementation and monitoring of their action plans in addition to implementation of their project specific objectives, as applicable. Dr. Lisa Shulman, a Developmental Pediatrician and consultant to Montclair will oversee the medical homes grants.

## **XI. Report of Revenues and Expenditures**

The report was included in members' Council packets, for information.

**Discussion:** A member asked about the \$4M in the Reserved Funding line item. Although the \$4M is still in reserve it will be taken out of the Autism budget by Treasury.

## **XII. Public Comments**

No public comments.

## **XIII. Adjournment**

Dr. Eggerding asked for a motion to adjourn.

**MOTION to adjourn by Dr. Aquino and seconded by Mr. Macchiaverna was approved with all in favor.**

The meeting was adjourned at 8:55 PM.